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ABSTRACT

This newsletter article describes early identification of children who have hearing impairments in Oregon. Oregon was selected to demonstrate a model system for early identification that had been developed in Utah. A new birth certificate was designed, which enabled the Oregon Health Division to screen for risk factors for hearing loss. A statewide advisory committee helped project staff in determining hearing screening protocols, payment systems, referral systems and sources, and information to be sent to parents and physicians. Hospital records staff and public health nurses were trained on the new information included in the birth certificate. Community education activities were also conducted. When at-risk babies reach 6 months of age, their families are mailed notices recommending that their infants' hearing be checked. Of 44,007 births in Oregon in 1991, 8.4 percent were identified as at risk for hearing loss. Forty-three percent of the notices mailed to these families were returned. Data are not yet available on whether babies and families are acquiring services earlier because of the registry program. (JDD)

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TEACHING RESEARCH

• Special Education Activities •

Monmouth, Oregon 97361 • (503) 838-8391 • March 1993

The purpose of this newsletter is to share with you our activities and projects. Each issue features a different project or activity. This issue describes early identification of children who have hearing impairments and was prepared by Jean Attridge Josephson and William Moore.

A list of our demonstration sites and those who manage them follows:

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LOWERING THE AGE OF IDENTIFICATION: OREGON'S DESIGN AND PRELIMINARY RESULTS

The Background

My child was identified as hearing impaired much later than she should have been. I asked my pediatrician all the right questions--at 8 months, "Shouldn't she be turning to sounds?", at 12 months, "When will she use more consonants?", and at 18 months, "Could she be hearing only partial sound?" I got the wrong replies--"Let's wait and see", and "Relax! I think you're overanxious." At age 2, our daughter's hearing was evaluated, at my insistence. The audiologist diagnosed bilateral, severe, sensorineural hearing loss.

In my search for "answers," I read about the importance of early detection, and added guilt-of-late-diagnosis to my list of sorrows. But I also read an article about early identification using high-risk criteria (Mencher, 1975). I decided that Oregon needed a system to help parents and professionals identify hearing-impaired infants. In 1981, as a volunteer with the Junior League of Portland, I worked to establish a regional high-risk registry using maternal questionnaires. Seven hospitals participated, and over 40,000 mothers were interviewed. State wide advocacy followed, and many meetings, letters and phone calls later, my persistence was rewarded. Our activities received attention at the federal level, and Oregon joined the short list of states actively seeking to identify hearing-impaired infants. (Jean Josephson, 1992)

In 1988 the Commission on Education of the Deaf reported to Congress that to improve educational outcomes for hearing-impaired people, the age at which children are identified as hearing-impaired must be lowered. In response, the United States Department of Education and the Office and Maternal and Child Health (MCH) jointly approved the Early Identification of Hearing-Impaired Children Project at Utah State University. As part of the project, Oregon was selected to demonstrate a model system that had been in use in Utah for over 10 years. The Oregon Newborn Registry Project at

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Teaching Research, Western Oregon State College, was funded for three years, beginning June, 1989.

The goal of lowering the age of identification of infant hearing impairment was addressed in four ways: 1) to identify infants at risk for hearing loss and to notify their parents of the need for hearing screening; 2) to refer parents and health care professionals to local audiologists for reliable hearing screening; 3) to inform the community of early identification issues and available resources; and 4) to evaluate the effectiveness of a birth-certificate based screening and community awareness activities designed within the project's duration.

So that the impact of the Oregon Newborn Hearing Registry could be evaluated, a study was conducted in May, 1990 to determine the patterns of identification of 6-year old children already in programs for the hearing impaired in Oregon. Average ages of suspicion, first hearing test, confirmation of loss, first habilitation, and first amplification were determined. Oregon's average age of confirmation of hearing loss was 30.6 months. Long periods of delay between parental suspicion and ultimate entry into a program for the hearing impaired were also noted (Moore, Josephson & Mauk, 1991).

A similar survey to determine the efficacy of Utah's birth certificate screening program was performed by Utah State University for the state of Utah in early 1990. For more than 10 years, Utah had screened birth certificates for risk factors for hearing impairment, and alerted parents to the need for hearing testing (Mahoney & Eichwald, 1986). Results indicated that on average, hearing-impaired babies born in Utah were fitted with hearing aids and enrolled in parent-infant programs before families in Oregon were even voicing suspicions that something was wrong (Moore, Josephson & Mauk, 1991).

Oregon's Design

Various communities around Oregon had attempted, at one time or another, to screen babies for risk factors for hearing loss and to notify parents and physicians about the advisability of hearing testing. The need, however, for a state wide, coordinated system was widely recognized. The MCH grant made possible the design and development of a project, and gave credibility and authority to those seeking to establish a comprehensive program in Oregon. The Oregon birth certificate was revised in 1989, and the new certificate circulated in January 1989 included a question about family history of hearing loss. The expanded birth certificate enabled the Oregon Health Division to screen for all the risk factors for hearing loss identified by the Joint Committee on Infant Hearing.

A state-wide advisory committee, composed of state agency representatives, audiologists, educators, and parents was assembled to assist the project staff. The committee helped determine hearing screening protocols, payment systems, referral systems and sources, and information to be sent to parents and physicians. Researchers experienced with high risk registries from the Utah Health Department and Utah State University met with the advisory group to share their experience.

Utah's system is self-contained within the Department of Health. MCH block grants are used to pay for birth certificate processing, parent notification, appointment staffing and hearing evaluations (Mahoney and Eichwald, 1986). Because Oregon's funding was temporary, and the state Health Division has no facilities or funding to test hearing, the design necessarily focused on using existing community resources and as few new administrative systems as possible. The state Health Division designed the data processing procedures and facilitated state wide training sessions for hospital records staff and public health nurses on the new information included in the birth certificate. Infant hearing issues and the Oregon Newborn Hearing Registry procedures were highlighted with slides, video and personal presentations. The Adult and Family Services Division approved the use of Medicaid funds for initial hearing screening without prior physician authorization for infants identified as "at-risk" by the registry. A coalition of local health officials voted to support the registry by serving as the referral sources for parents seeking assistance in arranging appropriate audiological testing.

The community was encouraged to comment on the design. Meetings with officers of the various medical societies, as well as articles in newsletters, sought opinion and support from physicians. All licensed audiologists in the state were invited to review the project procedures and hearing screening guidelines. Of the 138 audiologists in Oregon, 40 agreed to participate, and a *Directory of Audiological Services for Infants* (Teaching Research, 1990) was printed and distributed. The directory listed, by county, information about private or agency-affiliated audiologists, including location, hours, fees, and services.

Every city with audiological services has at least one audiologist participating in the registry. The average cost of an initial hearing screening using visual reinforcement audiometry, the screening protocol, is about $37. Families bill private insurance; Medicaid covers an initial visit; and the Child Development and Rehabilitation Centers in Portland and Eugene will test any infant "for no out-of-pocket expense" to the family. Screening is offered for no charge by 80 percent of the participating audiologists if the family lacks funds.

Beginning with August 1989 births, Health Division computers scan birth certificates for risk factors. The Joint Committee on Infant Hearing's 1990 Position Statement (American Academy of Otolaryngology-Head and Neck Surgery, 1990) serves as the basis for risk selection. Positive responses concerning conditions or complications of the pregnancy, and/or delivery, are computer coded according to the International Classification of Diseases (ICD-9). When identified at-risk babies reach 6 months of age, their families are mailed notices recommending that their infants' hearing be checked. A letter explaining the program was carefully worded to stimulate action but not alarm, and is written at a fifth-grade reading level. Because there is no information on the birth certificate about language spoken in the home, the notices are in English. The letter gives the parent five choices for response: 1) "Please contact me to have my baby's hearing tested. (A public health nurse will call you to help make an appointment)"; 2) "I will set up my own appointment to have my baby's hearing tested by an audiologist." (Note: audiologist is defined in the letter); 3) "My baby's hearing has already been tested by:" (space for name of audiologist and results); 4) "I do not want my baby to have a hearing test"; or 5) "The information on the birth certificate is not correct." A stamped, return envelope is provided for reply. If no response is received within two months of the first letter, a second identical letter is sent.

After about one year of registry operation, the Health Division staff suggested several refinements to the parent notification system. Listings from the *Directory of Audiological Services for Infants* were reduced in size and

made to fit on a double-sided sheet of paper, to be included in each parent mailing. This gives parents direct information on audiologists' locations and fees. The toll-free MCH hot-line telephone number that is required in each state was added to the letter. The hot-line staff received training in infant-hearing issues and their multilingual, 40 hour per week assistance to parents makes information more accessible and eases the telephone work time for many public health nurses.

Results

The State Health Division records how many parents return letters to the registry, and what their responses are. On average, 46% of the notices mailed from the Health Division are not returned. Eleven percent are undeliverable. Parents who respond to the notification by returning their form comprise 43% of the group.

In studying the response patterns of parents who did return their forms, the inclusion of the audiologist information sheet seems to have a positive influence. The number of parents requesting public health nurse assistance in making an appointment dropped from 46% to 32%. Parents who indicated they would make their own appointments increased from 20% to 28%. Disappointingly, only 9% of the high-risk 6-month-olds were reported by their parents to have already had their hearing tested. 12% of the parents selected, "I do not want my baby to have a hearing test;" 13% of the parents who responded said that the information on their baby's birth certificate was incorrect.

There were 44,007 births in Oregon in 1991. The Health Division birth certificate screening identified 3,682 infants (8.4%) as high-risk for hearing loss. Family history was the only factor in 1,084 (29%) births; 2,606 (71%) had multiple risk factors. It is important to remember that in the Oregon program, audiologists voluntarily report findings to the Health Division on all infants screened. Only 188 infants, or 5 percent of the total high-risk group, had audiological evaluations filed with the Health Division. Fourteen of these infants failed the initial evaluation. The average testing age was 9.5 months.

But has the age of identification been lowered? As a parent, this question has been my constant focus. It has been interesting for me to study notification response rates and audiologists' reporting patterns. Tinkering with the wording of a letter, and surveying parents to learn if they really do make appointments for hearing screening when they said they would, have all been part of the research. But the issue for me has been whether babies and families are getting into services any earlier because of the registry program. (Jean Josephson, 1992).

Oregon's baseline study showed an average age of 30.6 months for confirmation of hearing loss when looking retrospectively at the 6-year-old population. The question of whether the Oregon Newborn Hearing Registry has made an impact on families cannot be answered, therefore, until the first infants to participate in the system reach 6 years of age, sometime after 1995. However, in an effort to evaluate the project sooner, the nine parent-infant programs in the state have been queried about enrollment patterns since the registry began. Forty-four children, born after July, 1989, are being served in programs for the hearing-impaired. Thirty-eight were born in Oregon. The average age of confirmation of hearing loss for those born in Oregon was 11.3 months. Program staff reported risk factors for 27 of the children. Hearing losses range from mild to profound. Because such a high percentage of the children in programs have risk factors, the project may indeed have improved the identification rate for the at-risk population. The concern for infants without risk factors, who have yet to be identified, remains.

Much of the Oregon Newborn Hearing Registry project effort went toward community education. For example, an insert for the "Congratulations on becoming a new parent" packet was distributed by the Oregon Health Division to every mother at the time of birth. It describes developmental guidelines for language and communication skills, in English and in Spanish. Project staff conducted sessions for numerous hospital staffs around the state, describing the registry goals and alerting physicians and nurses to infant hearing issues. A 19-minute video, "Early Identification of Hearing Impairment: The Difference is Dramatic," produced with the assistance of a local television station, has been distributed to all county health departments, regional education agencies, and many other audiences. Activities for "May is Better Speech and Hearing Month" were coordinated in the Portland metropolitan area, with mass transit signs on buses that read, "The Sooner the Better--Have Your Child's Hearing Checked." A 6-month old baby posed as the visual feature. From speeches and magazine articles for parents, to formal medical and educational conference presentations, much effort was expended to educate the community about early identification of hearing loss. At the termination of the federal funding, the state Health Division agreed to continue to screen birth certificates for risk factors, and to notify parents by mail that their infants are at-risk for hearing loss, as part of their broader high-risk infant monitoring program. Community awareness activities continue to be the responsibility of state and private agencies that serve children and families.

Our now-profoundly deaf daughter would not have been part of the Oregon Newborn Hearing Registry; she has no known risk factor. But I hope that my questions to the pediatrician would be answered differently, 16 years later, due to increased physician education and awareness of audiological testing accessibility and accuracy. I am confident that in the years I have spent publicly campaigning for improved identification procedures, some infants in Oregon have been diagnosed at a younger age. I look forward to 1995, when we can begin to document whether birth certificate screening for risk factors does lower the age of identification of hearing impairment, and whether we are satisfied with that level of improvement. (Jean Josephson, 1992).

References

American Academy of Otolaryngology-Head and Neck Surgery. (1990). Infant hearing screening program launched. The Bulletin of the American Academy of Head and Neck Surgery, 9(9), 46-47.

Commission on Education of the Deaf. (1988, February). Toward Equality: Education of the Deaf. Washington, DC: Author.

Mahoney, T. & Eichwald, J. (1986). Model program V: A high-risk register by computerized search of birth certificates. In E. T. Swigart (Ed.), Neonatal Hearing Screening (pp. 223-240). San Diego: College-Hill Press.

Mencher, G. T. (1975). Nova Scotia conference on the early identification of hearing loss: A review. Human Communication Journal, 3, 5-20.

Moore, W., Josephson, J., & Mauk, G. (1991). Identification of children with hearing impairments: A baseline survey. Volta Review, 93, 187-196.

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